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AUTHOR Hausslein, Evelyn, Comp.  
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## ABSTRACT

This issue of the "Early Childhood Bulletin" describes some of the ways in which parents are learning to speak out on behalf of young children and their families being served through the Individuals with Disabilities Education Act (IDEA) Part H early intervention programs. The document consists of four sections in which parents share their perspectives and concerns. These include: (1) "A Call for Communication" (Christel Dawkins); (2) "Supporting Parent Participation at a Parent Organization" (Cassie Johnston); (3) "Supporting Local Parent Networks" (Mona Freedman); and (4) "Dreams and Visions First" (Judie Walker). Information about each parent's background, organizational affiliation, and role is included. (SG)

COALITION QUARTERLY  
EARLY CHILDHOOD BULLETIN

SUMMER  
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INDIVIDUAL VOICES, COMMON VALUES

By

EVELYN HAUSSLEIN

Compiler

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# EARLY CHILDHOOD BULLETIN

*News by and for Parent Members of State Interagency Coordinating Councils*

Summer

Prepared by Parent Component Staff of NEC TAS

1993

## INDIVIDUAL VOICES, COMMON VALUES

By Evelyn Hausslein

NEC\*TAS at the Federation for Children with Special Needs

Many parents across the country are speaking out on behalf of young children and their families being served through Part H early intervention programs. Many other parents, some with a little more experience in speaking out, are supporting these parents in their work. At a NEC\*TAS-sponsored meeting held in Arlington Virginia, in January, a small group of parents working with families receiving Part H services met to discuss the many ways parents were finding their voices and how organizations were enabling these voices to be heard. As we talked together, we realized that our small group was receiving a variety of organizational supports representing several different approaches to serving families under Part H. Although each of us at the meeting had different roles and responsibilities, we discovered that we all espouse a common value of empowering parents to speak up for their own families and for others, and to have a voice in the design and delivery of early intervention services in their states.

One of us was an ICC parent. Another was hired by her state's lead agency for Part H to reach out to all families served through Part H in her state. Others worked in their local Parent Training and Information (PTI) centers providing training and information to families on their rights and responsibilities under Part H. We generated a lot of energy and learned about important resources by sharing ideas from each other.

In our discussions we found that, although our activities and roles varied, our work was shaped by several values we held in common. All of us believed in the importance of: reaching families as early as possible; providing peer support through parent-to-parent linkages; extending the philosophy and promoting principles of collaboration at the local level; and encouraging active parent participation in local policymaking and interagency collaboration.

This issue of *Early Childhood Bulletin*, written by three members of the group plus Judie Walker who was not at the January meeting, describes some of the ways parents are finding their voices. We hope that their insights and suggestions will provide useful guidance to other ICC parents and Part H staff. Each author offers challenges for future growth.

Christel Dawkins was a parent member of the Louisiana ICC. Being an ICC parent member is perhaps the most well-known role for parents speaking on behalf of young families in Part H. There are many ways states provide financial and organizational support for their ICC parents. (Please see "State Support for Parents on ICCs" in the Spring/Summer 1990 issue of *Early Childhood Bulletin* for more information on this topic.) Christel has attended the annual Partnerships for Progress Conference twice as well as other national meetings of ICC parents.

Cassie Johnston is a staff member of Washington PAVE (Parents Are Vital for Education), the PTI center for Washington state. Her position as a Coordinator for the Birth to Six Project is supported by Part H funds. She describes her evolution as a trainer and some of her many activities in that role.

Mona Friedman was hired by the Maryland Part H lead agency as coordinator of the Family Support Network to provide outreach and training opportunities for parents and others working in Part H. About one-third of the states have used Part H monies to hire parents to conduct outreach and training.

Judie Walker is co-director of Pilot Parent Partnerships, the Arizona PTI which has a parent-to-parent program serving parents of young children. Pilot Parent Partnerships is also the new TAPP Focus Center on Early Childhood.

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# A CALL FOR COMMUNICATION

## PERSPECTIVE FROM THE ICC

By Christel Dawkins, Parent and Former Member  
Louisiana Interagency Coordinating Council

As a parent member of the Louisiana Interagency Coordinating Council (ICC) for early intervention, I have seen parent/professional communication at the state ICC level develop over time. This ICC communication has resulted in mutual trust, understanding, and respect. At this point, every ICC subcommittee, project, training opportunity, grant proposal or request, and state planning activity has parents participating as full members.

My concern has to do with the need to create similar opportunities for communication between parents and professionals at the local level. On a personal level, I remember how five years ago my child's therapist went out of her way to work with me. She not only taught me what I needed to know to make a difference for my own child; she also provided the insights I needed to work effectively with other professionals.

I am concerned that the demands on state systems for early intervention services, combined with severe shortages of trained personnel and limited financial resources, will make such parent/professional mentoring and communication nearly impossible. Where will the time, people, and resources be found? Furthermore, how can we justify asking for opportunities to develop parent/professional communication when there are so many other compelling needs? Yet this is exactly the time when such communication and collaboration is most needed.

In this time of scarce resources, one undervalued

resource is parents. Parents have important contributions to make, but not in the way ordinarily imagined. We are not junior service providers. What we do know is what the appropriate outcomes are for our families and what works best for our individual children.

I believe that many of the negative assumptions and misunderstandings would simply evaporate if parents and professionals got to know each other. Trust and respect for each other's expertise would be a natural result of increased understanding. Similarly, in program and policy development, parents' importance as resources will only be realized with deliberate attention given to fostering parent/professional collaboration.

Some suggestions for developing parent/professional communication skills outside the arena of an IFSP meeting are: to support parent involvement in local Part H planning teams, to include parents as participants and trainees along with professionals in pre- and in-service training, and to have families train students in all related fields to serve as respite workers or in other roles.

What is in place now in most states works for a few. Part H is about bringing quality services to *all* eligible children and families. Opportunities for parent/professional communication and collaboration are part of this quality service and will be crucial to fulfilling the promise. It is time to address this need in a meaningful, systematic way.

# SUPPORTING PARENT PARTICIPATION AT A PARENT ORGANIZATION

## PERSPECTIVE FROM A PART H EMPLOYEE IN A PTI

By Cassie Johnston, Coordinator  
Birth-to-Six Parent Project  
Washington PAVE, Tacoma, Washington

I have been a parent consultant in Washington state for the last five years. For the past four years, I have worked at Washington PAVE with funding for my position coming from Part H of IDEA allocated to my state from the Federal Government.

The original idea was to use Part H funds to hire two parents who had children with disabilities to support and encourage parent involvement and participation in the development of the statewide system for early

intervention. One parent would have a young child in the birth-to-six age range, and the other would be a veteran parent with an older child. I was the parent with the younger child. Suzanne was six years old. My veteran parent counterpart and I were titled Associates for Consumer Participation. At the time I was unable to work a lot of hours, so I worked ten percent time and my partner worked ninety percent time. I was considered a part-time, temporary state employee.

During the first year we devised an application process for recruiting parents for the State Interagency Coordinating Council, developed a notebook for ICC members, and provided training and information on P.L. 99-457 (now referred to as Part H of IDEA) to the first ICC parents.

The second year I increased my hours to work half time and my counterpart decreased her time to fifty percent. My position at PAVE was supported through a contract with my county Public Health Department's division of Children with Special Health Care Needs, High Priority Infant and Tracking System. I worked primarily at the state level, however, providing support and mentoring to ICC parents and representing a parent perspective among Part H staff members. That year I found myself advocating for information and funding that would help parents be active participants on the ICC. I wrote letters to agencies so that all the parents who had an interest in attending the Partnerships for Progress conference on Part H and Section 619 of Part B held in the Washington, D.C., area could attend. I also proposed funding so our parents could attend several state conferences.

Before becoming a paid employee at Washington PAVE, I had done volunteer work for at least three

years and had attended many of the PAVE workshops and conferences. PAVE's support was critical for me in those early years with my daughter. I was also a Helping Parent with my local parent-to-parent group. The work I was doing fit well with the philosophy of the PTI.

In the beginning my work felt like a dance. I was afraid of stepping on toes. But then I realized that people hear different music and dance to the music they hear. I have learned to hear and dance to a lot of different music over the last five years. Some I like better than others, but I respect it all.

This year, at the request of Part H staff, I will work fulltime. My counterpart has moved on to another project. A broad statement of work for this position was developed by Part H staff and me. The statement reflects the value of family-centered philosophy and practice. It calls for parent involvement at all levels, and for collaboration among all agencies, parent organizations, and early childhood professionals. But most important to me, it promotes and supports the idea of a continuum of parent participation, recognizing it as an enduring value that can occur in many ways. The best way to support parent participation on many levels is through a parent-driven organization.

## SUPPORTING LOCAL PARENT NETWORKS

### PARENT PERSPECTIVE FROM THE LEAD AGENCY

By Mona Freedman, Coordinator

Family Support Network

Maryland Infant and Toddlers Part H Program

My experience as a parent employee of Maryland's Infants and Toddlers Part H Program has presented many exciting challenges. I coordinate the Family Support Network within the Maryland Infants and Toddlers Program, and have started a grassroots movement to support families at the state and local levels. Our state lead agency for Part H is the Governor's Office for Children, Youth and Families which established the Maryland Infants and Toddlers Program (MITP). Maryland's Family Support Network operates from MITP's office in downtown Baltimore. This location has several advantages. It provides access and exposure to a great number of parents and ready access to a centralized data base.

To date, the Family Support Network includes over 400 families in a statewide database. I have provided direct support as staff liaison to over 60 parents of Local Interagency Coordinating Council (LICCs). I have also

developed a training guide for LICC Parent Representatives, and speak all over the state to promote public awareness among parents and professionals and to educate direct service providers and registered day care providers on the needs of infants with disabilities and their families.

While Part H has generated and supported change at the state level, we are now shifting our focus to the local level. Local family support networks must be developed to help inform parents about the services available to their infants and toddlers with special needs and their families. Fortunately in Maryland we have a great number of support and referral groups available, mostly free of charge. However, parents are often unaware of these services. Additionally, many agencies serving families of children birth through age twenty-one find it increasingly difficult to serve the many new parents of very young children.



Acknowledging that locally based family networks working out of local infants and toddlers programs would have a much better chance of reaching parents faster than one centralized network, we have initiated five Local Family Support Networks. We hope that at least three more counties will have local family support networks in operation by the end of 1993, with an ultimate goal of establishing statewide such local networks.

Our experience in Maryland shows that there is a strong desire among parents at the county level to participate in local family support networks. Using trained "veteran" parents of older children with disabilities as coordinators, local networks have access to all new parents entering the system and can link

them immediately with existing support services.

Establishing such networks seems to be the next logical step in fostering effective communication between great numbers of parents and professionals in the community. A parent coordinator from a given community would be thoroughly familiar with local supports and services, parent organizations, and parents and professionals involved in local programs. Therefore, localized networks will give parents information on more choices and immediate options.

We know now that parents who have learned how to network and support each other become better able to solve their own problems and rely less on professionals. The more informed parent naturally becomes a more effective member of the decision-making team.

## DREAMS AND VISIONS FIRST

### Perspective from Parent-to-Parent Support at the Parent Center

By Judie Walker, Director

Pilot Parent Partnerships

TAPP Focus Center on Early Childhood, Phoenix, Arizona

At Pilot Parent Partnerships, we recognize that families of babies and young children may not seek us out for information on "their rights" or even about "what they need to do." We have learned, however, that if we ask them what their dreams and visions are for their child and family — and really listen — then we can share with them the ways in which the laws, such as IDEA, can help them achieve those dreams.

When parents are beginning to find out about their child's disability and special needs, they often hear all that is wrong — what the child won't or can't do. It isn't always true that parents are devastated by the fact that their child has a disability or by the label itself. Rather many are devastated by all the negative things that people say or by the condolences they offer. By talking with another family who has a child with similar needs, families begin to see a more balanced picture. Maybe they *will* smile and laugh again. They learn they will be able to be a family — not by someone telling them how, but by living example. Families find out they are not

alone. The experienced family offers the new family information and support that helps break the initial isolation.

In our efforts to reach families we look at where families are and what we can offer to support their growth as a family. For some of our Spanish speaking families it means going to their homes and communities wherever they are comfortable. We get acquainted by listening to them first and offering information they request. Only after establishing this personal relationship will parents call us. To establish the initial contact we inform community physicians, health care providers, and human service workers about our work and how we might enhance their efforts to build a relationship with the family. We model respect for the family and family decisions.

Pilot Parents Partnerships helps families of young children not by telling parents what to do, but by listening and offering information and strategies to help them address their priorities. We meet families where they are by remembering our own feelings of being the "new" parent. Furthermore we help families to create new visions of possible and desirable futures.

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